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ABSTRACT

Interviews with six disabled individuals from the Center for Independent Living in Berkeley, California are presented to explore myths and misunderstandings about handicapped persons. The individuals, who are partially sighted, physically disabled, and cerebral palsied, discuss their experiences growing up with a disability, attending school, coping with family and friends' reactions, and adjusting to social attitudes. Suggestions are made for helping to demystify disability for young nonhandicapped children. (CL)

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MYTHS AND MISUNDERSTANDINGS ABOUT PEOPLE WITH HANDICAPPING CONDITIONS

"I am a man of substance, of flesh and bone, fiber and liquids -- and I might even be said to possess a mind. I am invisible, understand, simply because people refuse to see me."

Ralph Ellison, The Invisible Man

INTRODUCTION

Today the United States has some twenty-three million invisible people. These people, the handicapped among us, are beginning to emerge and become visible as they move more freely on the streets and in the malls, airports, and schools of our society. But as a society, and especially as educators, we have much work to do. The lives of the handicapped must be made more comfortable and less constrained. We must meet their special physical needs and accept and integrate them psychologically and sociologically into a predominately able-bodied world.

It is interesting to note the derivation of the word "handicap" -- cap in hand. Until recently, society shuffled the handicapped off to mental institutions, special classes, agencies or schools where they could be neatly labeled and categorized according to their individual disabilities. Many of the services and opportunities that the handicapped recently obtained for themselves were achieved, no longer cap in hand, but through the determination and persistence of parents and friends of the disabled and of advocates who overcame great social, physical and psychological barriers. They began to open closed doors and to throw light upon many myths and misunderstandings which blind the able-bodied to the needs of this large segment of the American population.

The hardware -- the braces, wheelchairs, aids and canes -- of the handicapped ought to make them obvious. Isn't a disabled person tapping with a cane, wheeling along, or pulling and shuffling highly visible? And yet, as told again and again in the narratives that document this paper, few in our society want to see the person: the hardware gets in the way. The public often looks away with a slide of the eyes. Or they stare without seeing.

To move beyond the hardware and the pity, disability must be demystified. Over generations, and recently in media campaigns, misdirected efforts to help the handicapped continue to shroud the real people in swirling mists of myths and misunderstandings. The purpose of this paper is to reveal some of these myths and misunderstandings through the use of personal narratives to make visible unconscious blind spots. A unique opportunity is at hand to reverse the pattern of invisibility for millions of children. We have been given an opportunity to open a pathway of integration for children into society, a society which too often dictates that we all look, act and feel like the perfect beings who parade across television screens and smile their way through the pages and billboards of American culture.

In 1971, a group of disabled individuals joined together to form a center from which they could attempt to expand awareness and raise consciousness about the special needs of individuals with handicapping conditions. Choosing the roles of activists, these individuals at the Center for Independent Living in Berkeley, California, count among their victories a substantial increase in the community's awareness of the needs of the disabled. They also credit themselves with making a substantial contribution to the passage of state and federal laws expanding opportunities for special needs children and adults. In interviews* with six CIL individuals, we explored their personal educational, psychological and sociological experiences in American society over the past 25 years. We hope that by looking closely at their experiences, we may gain more understanding of their special needs and break through the barriers created by myths and misunderstandings.

*Interviews were conducted at CIL by Nick Rayder, Ed O'Neil and Suzanne Hering.

INTERVIEWS

Guy Guber, a Deputy Director at CIL, is partially sighted. Because of his premature birth, he spent the first four months of his life in an incubator where he received too much oxygen which resulted in the loss of most of his vision.

When Guy was old enough to attend school, his parents were dissatisfied with the available state school for their son. They wanted him to be educated in an integrated setting so they toured the country from New York to Tennessee to the Midwest to Southern California. They finally moved from Chicago to Berkeley where Guy could be mainstreamed and would be taught print instead of braille. They believed it important for him to use the vision he had.

In school, Guy was labeled "high partial" and that meant he could see more than someone labeled "blind." He says, "We avoided the blind like the plague. I just refused to associate with blind kids at all because I was continually taught that I was not blind, that I could see, that I had to use the vision I had. The problem with that is that I overcompensated. I wouldn't even wear glasses."

Guy liked school until the second or third grade when the teacher humiliated him for going up so close to the board to read the letters. His classmates' cruel treatment of a little blind girl at whom they threw food further alienated him from identifying with being blind. He would hide his large books and take them home to read.

At school he was always the last one chosen for a team or was not chosen at all. "I was always a social outcast and I had a skill for attracting bullies," he says. "In junior high school dealing with puberty was difficult. I think a lot of disabled kids get asexualized or desexualized. Because they look different, they get classified as something other than a boy or girl. I had already been stuck off someplace as an outcast and now I had to deal with the world of boys and girls and dances and dates. I remember asking a girl to dance



"It took me a long time to figure out that, yeah, I'm not blind, but I'm not sighted either."

and she said no and I sort of walked away dejectedly because I had a crush on her and I heard her say, "Oh, I can't dance with him, his eyes are all weird."

Guy says that as a result of his social experiences as a kid, he feels that he's warped, a social mutant. But he points out that that's okay because it gives him freedom. "If you're excluded from normal social interaction in your youth enough so that that affects your personality you are also sometimes outside normal limitations and expectations. There's an added dimension of freedom along with the flaws."

In high school, Guy became more involved socially and academically, but still could not fully accept his special visual needs. He says some of his new friends accepted him and accepted what he calls his neurosis. Some of school he found interesting, and some boring, but because of the help of his parents and because he was a good student, he planned to attend college. His high school counselor, however, advised him that he would not be accepted in the three or four colleges which later admitted him.

During the summer before he entered college, Guy attended a pre-college orientation program for students with special visual needs. Here he finally confronted the fact that the way he saw the world was real and valid for him and that his vision had a large effect on who he was.

Now as an adult, he still sometimes tries to pass as normally sighted. When he doesn't, he says people's reactions vary. Sometimes they are interested, sometimes polite, sometimes they don't mention it, and sometimes they are uncomfortable. In comparison with many disabled people he is only mildly disabled, but in terms of the world, he feels he's severely disabled.

Guy thinks his parents handled his disability pretty well. He points out that most disabled kids are born to able-bodied parents who have to begin accepting the child's disability at the same time the child does and parents are just human. "My parents pushed me to do things and were real hard on me as a kid. Because I was sensitive, it was a bitch on me. In some ways it wasn't fun to be made to do this and made to do that, but I beat the hell out of the alternative. They kept emphasizing the fact that I wasn't blind and it took me a long time to figure out that yeah, I'm not blind, but I'm not sighted either."

When asked how schools could help the disabled to a realistic acceptance of their disability and also to optimal functioning and social and psychological growth, Guy says that he thinks role models are important for both disabled and able-bodied children. "The disabled person in a position of authority might encourage able-bodied children to treat the disabled with a little more respect and humanity. And for the disabled kids, role models would provide some kind

of heritage for them. Disabled kids don't have a reservoir of wisdom to draw from or to be part of. I think that feeling of continuity is real important for kids. Helen Keller is okay as a model and inspiration for the blind, but there's no one for the partials, for instance."

Parent counseling is also important, says Guy. He recalled one student in a program in which he worked. The child was kept in a room with nothing but pillows so he wouldn't hurt himself -- for the first five years of his life.

Despite the federal mandate to mainstream disabled children, Guy says that it's still an able-bodied world and it always will be. The disabled will always be "flawed folk. I'm a flawed individual both physically and emotionally and that's what I have to deal with. I'd like to see young kids avoid the warping process. I'd like to see them not have to go through that. It's way too good a life to do that."



photo by Debby Hoffman

"I think if you're going to have disabled people in positions of authority in public schools you're going to start seeing some attitude change around disability."

J. Corbett O'Toole, a CIL activist, contracted polio when she was a year old. Despite her crutches and braces she was accepted in public kindergarten. She remembers that her teacher "freaked out" and took a special summer school course to prepare specifically for her. "The teacher had learned that handicapped children are immature for their age and that red is a significant indicator of the immaturity of the handicapped child. She latched onto this theory to explain all the red pictures I painted for my mother. In retrospect, my mother thinks this is funny, but at the time it wasn't. My mother finally decided to ignore her analysis of my personality."

Corbett grew up in a suburb of Boston in a working class Irish family and after her initial experience in public school, she attended 12 years in parochial

schools. For the first two years, her mother walked with her to carry her lunch box and school books until she learned that the school district was responsible for transporting her to school. The only disabled child in her classes, Corbett recalls no conflicts in the classroom. She was able to spend five hours a day sitting with her hands folded, saying prayers and having her questions answered. Her disability didn't affect her ability to sit passively and soak up her education.

During her school years, when she walked on the street, Corbett noticed people staring at her while at school everyone pretended she wasn't disabled. As long as she pretended and they pretended, she was not forced to confront her special needs. Her problems with this avoidance intensified, however, in high school when sex roles became more clearly defined, and then it became clear to her that she was different and she didn't fit in.

"I was supposed to be beautiful. I developed a lot of resistance toward certain roles. I became separate and didn't deal with that in terms of my disability, but rather I used my personality to explain away reactions that troubled me. I said they don't like me because I'm too smart, or because I talk too much.

"When I was sixteen I started working at a Y where everyone was an outcast in some way. And at school I developed friendships with kids who came from the wrong side of the tracks, kids who were too easy, kids who were the slowest, the ugliest. I was validated by being an outcast."

In reflecting on the attitudes of her parents, Corbett says she wishes there had been some way her parents could have helped her integrate the skills she needed to function in an able-bodied world as well as validate for her a feeling that she was not totally nuts. She also wishes they could have assured her that "I wasn't going to be cured and that was, in fact, not a goal."

When trying to make a decision about college, which her parents couldn't afford, Corbett learned that the Department of Rehabilitation would pay her expenses, so she enrolled in a state teachers' college. She had become interested in teaching partially as a result of her affiliation with a summer camp she had attended for several years. Here she had associated with other disabled people. "There wasn't a lot of validation in terms of adult role models, she says, but there was a lot in terms of being with other disabled people." When she joined the camp staff years later, she was the first disabled staff adult.

"Of course, what should I do but teach mentally retarded, help the handicapped, just spread it around. I got out of that eventually. I realized that I was into a helper role in a way that I didn't feel good about. I realized that the educational system retarded people go through is a real oppressive system and I didn't want to be supporting that. Then I worked with emotionally disturbed children for awhile. That wasn't a whole lot better. Finally, I began working with preschool, nondisabled kids."

She continues, "Since I've been involved with the disabled movement in Berkeley, I'm lots more comfortable talking about my differences. I try to be open and up-front with the nursery school kids. They ask questions and I try to answer them. I call my cane a walking stick with them, for instance. That puts disability in a more positive light. I try to give them a positive vocabulary around disability."

"Adults have more problems asking questions than the children. They're embarrassed. I personally think what we can do with adults is limited. When mainstreaming was passed, I was in my last year of college with other students finishing their elementary education courses and I heard them say, 'I'm never going to have one of them in my class.'"

"So I have mixed feelings. I think if you're going to have disabled people in positions of authority in public schools you're going to start seeing some

attitude change around disability. I don't think nondisabled people can teach other nondisabled people about disability in any real way. Disabled people have to be involved at all levels. Also, people with different kinds of disabilities are needed because the kinds of people who are probably going to get into the schools are people who can pass real good. I think after you get the people into the schools, then it becomes realistic to talk about materials. The materials without the integration just won't work. A token person won't work either. One person can't be all things to all people," she says.

"I have very definite ideas about what will work and what won't work. To sensitize parents of integrated students you need a dialogue with them to determine their needs. What problems are they worried about in the classroom? I usually start by having adults who are representative of the types of disabilities that will be found in the classroom give five or ten minute raps about who they are. Then I ask parents to state their concerns. I think in each school community you'll have a different set of needs.

"One of the things you'll run into is fear and anger. Lots of teachers and parents believe a lot of myths about disability. They think the disabled child will take up too much time, the kid's going to be slow, they're not going to be able to get rid of this kid because everyone will think poorly of them, the other kids will make fun of the child, and everyone's going to be breathing down that teacher's back.

"For the most part, adults in general, hold so many misunderstandings and have so much pity that they're hard to deal with. I feel more hopeful working with kids. Their staring is the most open and truly inquiring. They really want to know, to learn."



*"People just slide their eyes
by you, don't want to face
disability, don't want to see it."*

Ed O'Neil, a paralegal advocate and trainee specializing in educational disability law, spent nine months in an iron lung. He contracted polio in the summer after his first year in Catholic school. At seven, he could only move his head and swallow. He recovered to some extent, then spent three years in a rehabilitation center where he learned to walk again. While in the center, in addition to exercises and therapy, he was tutored. "That was a joke. All I remember of that tutor was that we did things like compile lists of spelling words for three years. She'd give me some problems out of workbooks once in a while, and we'd have a spelling test every week and that was about it. I had a story book I could read and I was a

good reader so that's what I did. Then I went back to Catholic school in the fifth grade. I felt raw going into the classroom again. I did have some friends there from before, but it was so hazy, so far in the past. The kids were all nice and the teachers were all nice and it was very sheltering and protective. I stayed in that school until the eighth grade.

"In the middle of my freshman year in high school I went into the hospital for surgery on my left arm. This was a surgical success. But I was lied to by the doctors. I was treated as a thing, not as a child. The doctors told me I was going to have one operation and I would be out in two to three months. But I was there for six months. I hate hospitals. I have a strong aversion to institutions because of my being in them for such long periods of time."

During the six months Ed was in the hospital, a tutor worked with him. "That was a joke, too. All I did was make lists of synonyms and antonyms. Also, she would give me things to do to take up time. She would have me make up as many words as I could out of longer words like hippopotamus. I wouldn't call that teaching. I was taking Latin and she was supposed to keep me up on that, but she couldn't. All I did was memorize vocabulary. Each week I would have five more Latin words, so that when I finally did go back to school, I had a fine

vocabulary, but I didn't know anything about conjugation. When I returned to high school my teacher assigned another student to me to help me, but I finally figured out that he resented me. It wasn't a good relationship."

In high school, Ed could write, so he got by. What he experienced he terms "benign neglect." In physical education, he usually went to the principal's office to read or a couple of times went out to the football field and just stood around. "I felt a little weird about that because everyone was doing something and I wasn't." He took typing and learned to type pretty fast with one finger.

Ed studied radio and television in college for one year because someone told him he had a resonant voice. After barely passing the first year with C's and D's, he began taking courses that interested him and teaching himself how to study. He said he didn't know how to write a paper. In college he began to mature and to think seriously about what he wanted to do. He decided he would like to teach. At the end of his student teaching, in his final year of college, his master teacher who had observed him sporadically at the beginning of his teaching and at the end told him that his discussion of the civil rights movement and racial issues was too difficult for his students. In the Contemporary Problems class he should have been teaching them how to keep a budget and balance a checkbook. She told him that she would not recommend that he become a high school teacher, that he should consider teaching on a college level.

"After it was over I was shaking and I was really angry, but I didn't know what to do with it. I wanted to come back and attack her, but I didn't know if I should, so I returned to school and my college supervisor took care of it. That doesn't really have anything to do with disability. It just happened.

"However, let's get back to the topic of the influence of my disability on my career. In one job interview with a school principal when he asked me if there were anything I couldn't do in a classroom because of my disability, I told him that I wrote with difficulty on the blackboard. I told him that I didn't use the blackboard very much, but that when I did, I asked a student to write on it for me. He replied, 'Oh no, no, no. Teachers have to use the blackboard. You have to be able to write on the blackboard.' I'd always ask the kid who was the discipline problem to write on the board."

Ed says that his family sheltered him. "No one wants their child to be disabled, so when I became sick, they were affected. They internalized an attitude prevalent in this society about disability. There was a consciousness of feeling sorry or protecting me and I wish that they hadn't sheltered me so much. Like my teachers, they just didn't know what to do.

"I spent a lot of time when I was young trying to pass. That is, not to be recognized as a disabled person. If I could get on a bus or walk down a street and not be looked at or stared at that made me feel like I had really done something. I spent a lot of time having an image of myself as an able-bodied person and thinking of myself in that way. If someone noticed me or stared at me it made me feel so self-conscious that I could hardly stand it and I guess that's one of the lessons of my life. I don't feel that way now. I guess I was affected by living in America and by seeing those beautiful, able-bodied images that are projected all over: the young, Hollywood beautiful women and beautiful men.

"I don't use a tie anymore. When I was practice teaching in 1965 I was supposed to wear a tie. I spent more time worrying about how I was going to get my tie on than preparing my lessons. So I just decided one day I'm not going to wear a tie. It's not that big a thing. Then I felt better. I had released myself. My disability has forced me to try to put priorities on life values. It's made me realize that human values are more important than material values. If you treat people as sensitive beings then they'll be as sensitive as you are."

Ed believes some of the main positive outcomes of integrating disabled children and adults into classrooms would be to break down barriers and to set a priority on human values. "The more time and energy spent on demystifying disability and breaking down the illusionary barriers that separate the disabled from the non-disabled in every way would be worth so much. At the core of everybody, people are people. A disabled person is a person, but they've been separated, segregated, put off, labelled and put into compartments. Even in Berkeley where people are generally aware and progressive, people just slide their eyes by you. They don't want to look at you, don't want to face disability, don't want to see it. I can understand that and I'm not saying that this should be met head on, but do sensitivity training with kids. Bring the wheelchairs into classrooms. Get the disabled into the world as much as possible so that they see people and interface with them.

"There are all kinds of myths around. Like one woman who asked my friend, 'Isn't it against the law for these people to have children?'"



"I couldn't go to some special classes because I didn't have the right label (cerebral palsy) and I couldn't go to public school because I was a fire hazard."

Judy Heumann, Senior Deputy Director at CIL, contracted polio when she was a year and a half old. Now she considers herself a disabled person and she says she doesn't know what it's like not to be disabled, but she does remember a time when she believed she was as mobile and frisky as the able-bodied children with whom she played. With them, she deluded herself that no one could see her wheelchair. With them she wasn't disabled; consequently she wouldn't associate with disabled acquaintances. She wasn't like them.

When Judy was old enough to enter kindergarten, her mother took her to her neighborhood Brooklyn school where the principal wouldn't admit her in her wheelchair because he said she was a fire hazard. When she was old enough to enter first grade, her mother found a

Hebrew school where the principal told her that she couldn't enter because she hadn't studied Hebrew. Her mother hired a tutor and soon Judy knew more Hebrew than her peers, but the second time her mother approached the principal, he was more honest. He didn't want Judy because she was in a wheelchair. So, at six, Judy began receiving home instruction.

"I couldn't go to some special classes because I didn't have the right label (cerebral palsy) and I couldn't go to public school because I was a fire hazard." For three years Judy received about 3 1/2 hours of education a week until "they liberated the special cerebral palsy classes and I got in as the first post-polio in that unit. We were all bused together and we all received the same inferior education. I was doing work at two to four years ahead of the other kids in the class because my mother had worked with me. So I started tutoring the other kids first because I was bored and second because the teachers weren't doing much.

So I had no math for four years and I remember in the summer I had to work with my mother and I used to hate to do it because I was really hating math at that point because I wasn't learning it."

Judy continues, "When it was time to go to high school -- I guess it was when I was in the sixth grade -- if you were in a wheelchair you didn't go to high school, you went back to home instruction because the schools didn't have transportation. So mother was real involved with some other women in meetings with the Board of Education and got the high schools to accept the disabled. It was at that time she quit the March of Dimes because she was trying to get a lot of the agencies that were providing services and fund raising to come in and be active in the public school system and the March of Dimes said they didn't get involved in anything but fund raising."

In her family, Judy was given responsibilities as were her three brothers. When she was 10 or 12, her parents no longer hired babysitters and Judy cared for her brothers. And as she grew up, her brothers assumed responsibility for driving her to lessons or to visit friends.

She says of her parents' early expectations of her future that, although no one ever talked about it, they expected she would marry. Yet, at the same time, they expected she wouldn't, so she developed a skill to support herself until a husband appeared to support her. For years she studied music, but music wouldn't provide a practical, steady income, so she relinquished that dream. Eventually, she became a teacher and taught in the same classroom where she had tutored students years earlier.

In commenting on the integration of the disabled into classrooms, Judy relates a comment a college professor once made to her education class. He said that his basic feeling was that it wasn't the teacher's decision to decide whether or not a person was going to be in his or her class. If the teacher was unable to handle that person in the class, it was the teacher's problem. If it meant the teacher had to be put someplace else or leave the profession that was what should happen. "I think that's a very cold, calculating kind of statement, but I really feel teachers are supposed to be people who are emulated and that if their prejudices are so overt as not to allow for a particular child or group of people to be able to function adequately in a class, and it can be shown that it is primarily the teacher's problem, then give the teacher some help, but otherwise it's time for the teacher to take a walk."

Judy points out that she feels you really have to talk about society changing. "Children learn from their parents and so you have to talk a lot

about working with parents of the able-bodied as well as the parents of the disabled.

"When I began teaching nondisabled children, I was viewed at first as being sick. It wasn't that the children didn't relate to me, but they picked up that word and that idea from their parents. I had been teaching these kids for about 5 months and it was Christmas. One of the kids came up to me and said 'My mother said to say Merry Christmas to my sick teacher.' I had no idea what the word 'sick' meant to her mother. She probably thought it was a nice term and said it in a nice way. It's easy to see how confusion arises when a child asks, 'What's polio?' and you say, 'It's a sickness.'

"When I was teaching I tried to be as open as possible and answer as many questions from the kids as they would ask. They would want to know if I could feel all over my body and I would explain that I could, but that there were other people who couldn't. I would try to explain that I could say to myself, 'Move my leg' but that the problem was like having a telephone with a wire that was cut. If you spoke into the phone the message didn't get to the other person and the connection wasn't made. I don't connect from my brain down to the movement of my leg. After a while the kids became very uninhibited about asking questions. When you fail to answer kids' questions especially around an issue where fear is involved, then I think all you do is foster that fear.

"One day we had this great lesson. Everybody was sitting on the floor reading a story. One of the kids raised his hand to ask a question, and when I called on him he asked, 'How do you go to the bathroom?' I really wanted to laugh, and I did a little, because I thought the lesson was involving the whole class, and here this boy wasn't thinking about the lesson at all. I answered the question for him, and then we went on. I think it's important for the students to know if they have a question about my disability it's okay for them to ask it, and they will receive an answer."

Judy didn't always hold that attitude, especially when she was younger. At that time, she had difficulty even acknowledging her disability. When someone asked her about it, it shattered the illusion that she was as able-bodied as anyone else. In addition, she saw her disability as "bad." Eventually, she came to accept her disability and the restrictions and frustrations surrounding it. She says, "I've gained a lot from being disabled. I've gained a lot of experiences that I think other people are not fortunate enough to have had. Interacting with non-disabled individuals and having to accept how they treat me and how I have to manipulate them in order to get them to understand about me and about disabled people in general has given me strength. I try to dispel myths around disability."

One myth she became aware of early in her life was the myth that she could not make decisions, that she was a perpetual child. In counteracting that myth, she says she tended to overcompensate. Another myth she negates is one fostered by the March of Dimes: if you're walking, you're better. This, she points out, gives the permanently non-ambulatory no hope. Because "to walk is better" and to cooperate with people around her who encouraged her to overcompensate, she didn't use an electric wheelchair until she was twenty one. Her weak arms made movement in her manual wheelchair a difficult and unnecessary struggle. She says she could have been more independent at a younger age if her parents had accepted for her the electric wheelchair someone offered them.

She points out that sometimes being disabled is confused with mental retardation. "I think the discrimination within the disabled community has been heavily against identification with people who are mentally retarded. The system fosters myths by grouping people into different categories of disability. Individual organizations developed to work with particular categories of disabilities actually separate the disabled and encourage resentments and isolation.

Another myth Judy encounters is the myth that disability is contagious. She often explains that she once had polio, but that now she is well, although the effects of her disease are obvious. Closely linked to this is the myth that disability is a punishment. She tells of the experience of an amputee friend who was stopped on the street by a mother with her child. The mother said to her child, "See what will happen to you if you misbehave."



photo by Ken Okuno

*"I appear as though I can see...
I got the message early on that
my disability was not a very
acceptable thing."*

Jeff Moyer, a Deputy Director at CIL, began losing his vision when he was four years old. Either a virus or measles attacked his optic nerve causing him to lose more and more of his vision over a period of seven years. At first, no one believed that he was having difficulty seeing. When he would hold a book or paper close to his eyes, his father would order him to hold it at arm's length. After all, they'd taken him to a reputable optometrist who could find no pathology on his retina. He had given four-year-old Jeff a non-literal test, and as far as he could determine, the youngster was pretending he couldn't see. Jeff had a reputation for fabrication and melodrama anyway, so it made sense that he might choose this way to get attention.

For the next three years, Jeff says, there was a lot of confusion. He could pass as being able to see and that was the "beginning of my denial which was something I spent twenty years grappling with. I appear as though I can see. I don't have a noticeable disability. Because I was punished for adapting the way I needed to, I got the message early on that my disability was not a very acceptable thing. As I lost more and more vision I was expected to do more and more things visually, so the visual demands and the size of the print crossed in the fourth grade and I couldn't keep up with the reading. I'd hate September because the print in the books kept getting smaller and smaller. It was a gradual slide toward blindness which was really frightening and socially very isolating."

About this time, Jeff's parents took him to a specialist and still no medical evidence could be found to explain his symptoms. "Also, there was never any emotional response to what was happening or any kind of support for adapting. The whole world of services for people with visual disabilities largely focuses on total blindness. There was virtually no attention in terms of services or programs or support -- until very recently -- given to partially-sighted persons.

I wasn't given any adaptive aids and devices that could have helped me early on, so the teacher wouldn't have had to write things down from the board, so that I would have been able to read more. That was never offered to me until I passed the magic threshold of legally blind. I was eleven years old. By that time, I had gone through four years of not being able to see.

"The other thing was that socially I wasn't able to compete. I was still trying to. I played baseball up until I was nine or ten. I really wanted to play ball, but I could not see the ball moving at all. I broke my nose playing catch with myself trying to improve my skill. I felt it was something that if I worked hard I could do. I really believed that somehow I was at fault. I internalized the feeling that I was doing something wrong because everyone else could do it and I couldn't and what was wrong with me. As soon as I hit myself in the face with the baseball, I quit. Something inside of me said it's just not worth it.

"When I was eleven, the eye doctor told my mother if I continued to lose my vision at the rate I was I would be functionally totally blind within a year and I had to learn braille and I had to learn some adaptive skills, so they put me in a special class in a school district 25 miles from my home in Cleveland. Every day a janitor from the school picked me up and drove me out to the school where daily I arrived an hour late. The teaching level was about two years behind where I had been, so I was repeating a lot of material and I spent half my day in the resource room learning braille with first graders, sitting at a little tiny table. I could see the damn dots and I refused to touch them. I said, 'I'm not blind, I can see.' I took the braille writer home, didn't touch it. I'd sit and put my face down to it. I did learn to type. That was the one skill I got out of that.

"After school that year I'd attend dancing school with my friends in Cleveland. Again, I got to class late. Everyone had been together all day and I felt out of it. Social isolation was the key factor. The other thing that happened that year was that the doctor told my parents that I couldn't see well enough to ride my bicycle which was another big loss. Not only could I not play sports, but I couldn't ride my bike with my buddies and I began to feel that anyone who related to me was doing so because they felt sorry for me. I felt I would take any friends I could get because I had lost a lot of social roles and was feeling pretty isolated. I never failed to scrape and bow and do whatever anyone wanted me to do and became pretty plastic in my affect because I really craved companionship."

When Jeff returned the following year to public school he brought his optical aids with him, but he was too embarrassed to use them effectively. He hoped that no one noticed him using them.

During his years in school, Jeff experienced a variety of reactions from his teachers and parents. One of his French teachers typed the whole French text and his tests in large print for him. She also took him aside and talked to him about the advantage of not driving. Secretly, he was praying the Ohio State legislature would change the driving age to 18 because all his friends were beginning to get their licenses. His parents and sister and grandmother and paid students in school read many of his lessons to him. With that kind of support, he began to find his school work much easier. Not all of his teachers, however, were so supportive. One English teacher told him the questions he couldn't read on the final test from the blackboard wouldn't be considered. Then the teacher marked them wrong. Jeff needed the B he missed in that course to enable him to apply to Antioch College. Another teacher assigned his students alphabetically and Jeff sat in the rear although he told the teacher he preferred to sit in the front. One day when Jeff didn't have his optic blade with him, the teacher wrote a problem on the board and said, "What's the answer to this, Moyer?" Jeff replied that he couldn't read it. "Don't give me that shit," the teacher said and continued to intimidate him. In another class in college the teacher wouldn't let Jeff tape the lectures although that helped him considerably to take notes later.

When he was old enough to begin dating, Jeff tried to hide his disability. "I felt that if I got a foot in the door, if I could get past the initial rejection, then if it came out later, I'd take my chances. I remember once how amazed I was to learn from a girl I'd gone out with three times that she already knew I was blind. I was floored. It was the first time I conceived that someone could know and accept me anyway. As I grew older, socializing became easier because I developed poetry and music. I was alone a lot and for awhile I didn't have many friends. I began developing music by ear. I fooled my piano teacher for over a year. He quit teaching me when he learned that I couldn't read music. I'd always made him play a piece first and I listened closely."

Even now when Jeff says he is pretty comfortable with his disability, he's still bothered by having to explain it when he first meets someone. Sometimes when he's talking his eye wanders to the right and the person to whom he is speaking may think he is talking to someone else. "I hate to have the first topic of conversation be my disability. And it's a difficult subject to get off. It brings up people's anxiety, people's fears, people's misconceptions,

people's feelings of their own discomfort, the stigmas, the stereotypes. All that stuff that they've internalized socially. Then it's my responsibility to get people past that.

"Sometimes when I know I'm going to encounter Joe Public in a visual way, I wear a disguise...a pair of dark glasses or I carry a cane. I can walk up to someone and ask a question more legitimately if I'm carrying a cane. I've developed being an actor of blindness. I use that when I feel that I can't deal with lots of explanations. It makes the encounter easier for me."

Jeff says that he thinks when teachers are trying to demystify disability for children, the best thing to do is let the disabled person interact with the children in a straight one-to-one interaction. The regular teacher should sit in the back of the room so he or she won't patronize or edit the exchange. It would be instructive, he thinks, for the disabled person to show adaptive aids and techniques, whether they're hearing aids or sign language or optical aids or braille or braces or wheelchairs. He thinks the emphasis should be on the functional aspects of the disability. And he thinks it's important to talk about the disability in terms of the adult's life so that the stereotype of the disabled as an eternal child is not reinforced.

"For instance, the poster child really reinforces the innocent child concept. Most people don't really see disabled adults as the ultimate outcome of disabled children."

Providing a variety of experiences for children is also important. "I contend that you don't learn anything about yourself as a person from getting good grades." He says there are a number of noncompetitive sports in which disabled children can participate as well as nondisabled kids. One is a game called beep ball where the skill is auditory rather than visual. Gymnastics, relay races, sighted guide walks, and trampoline work are all games that can help to develop positive body images and self-concept.

In reflecting about his education and his experiences with doctors and his parents, he points out that he was never consulted about many decisions. Too often, he believes, he was overprotected.



"Helen Keller is a wonder woman. A disabled person in the community functioning well in a career would be a more realistic kind of model."

Ten years ago when Pat Bentley was in her late twenties, multiple sclerosis began to limit her physical mobility. In her position at CIL doing Intake Counseling and Peer Counseling, she says she's heard some "really grisly stories about how ill-prepared people have been in special education programs." She has a teaching credential and has worked with mentally retarded children, some of whom were emotionally disturbed and physically disabled. She is a graduate student in psychology at Antioch College.

Pat does not share special education experiences with other special needs individuals at CIL, but she copes with similar social and psychological barriers. She says of her personal experiences: "MS is a progressive disability and it's up and down. I've had periods when I

wasn't able to walk, and then periods when I was more or less okay. And that's very confusing for people to deal with. It's hard enough for me to deal with, but for other people it becomes even more confusing. My problem is predominantly in my legs and with my balance.

"Recently a woman on Telegraph Avenue stopped and asked me if I were drunk. I find as soon as I use a cane it's a signal that I have something specific wrong with me, that I'm not just weird. The cane legitimizes me. Sometimes I use a chair if I'm going to a museum, for instance, and will be on my feet for a long time. I've had the experience of someone seeing me in a chair, and then a few days later seeing me walking. That seems to be real confusing for some people. For me, it's a convenience.

"I generally take the responsibility to talk about my disability if I feel it's appropriate. Or if I feel that someone is having difficulty around that.

"In my work, the main problems that clients talk to me about center around socialization. People who came through special education programs and then entered a regular school situation at high school or college level, or went all

the way through a special program then went out in the real world, felt they lacked the social skills they needed. At the same time they accrued social liabilities, they also accrued intellectual liabilities. They were usually not sufficiently challenged intellectually."

Pat believes that limited intellectual or professional expectations are unjustifiably placed on special needs students. Role models might counter this tendency, but she points out that role models should be realistic. "Helen Keller is a wonder woman. Her achievements are so incredible that most of us have trouble relating to them. A disabled person in the community functioning well in the business world or in a career as a professional would be a more realistic model." She points out, too, that stereotypes and expectations of the handicapped can be cultural. In Japan, for instance, blind people enter one profession -- acupuncture. Having broad expectations and offering alternatives as well as making children aware of their choices within the context of their actual abilities and limitations is important.

In helping able-bodied children to relate to disability, Pat recommends an open and direct approach. Children should feel free to ask questions. "I worked with a child who was an amputee. None of the other children had ever seen an amputee, and it was very frightening and threatening to them. As a special project this little boy wanted to give a report on his disability. He showed his prosthetic device and talked about his experiences. By the end of the session, the kids were not only very comfortable with him, but many of them were envious of this device that could do things that they couldn't do. It was interesting to watch because initially the kids were very anxious around him.

"Everyone wonders 'Do I ask what happened? Do I stare?' I think the interest is important. Most children think disability is something that happens to old people. Teachers are insecure, too: do I help the child off with his coat or watch him struggle? I think the more uniform expectations can be, the more every child benefits. Some special considerations have to be incorporated, of course, especially if the disability means that a child takes longer to complete work. But today with teaching aides it's not so important to make special considerations.

"Another effective method to help integrate special needs kids into the classroom is to use a buddy system, pair a child who may be disabled but strong in math with one who is slower in math. There's an exchange there. I always emphasized the ability rather than the disability."



"Get every kind of orthopedic equipment you can. Let the kids touch them. The minute we get them to touch something, we've won part of the battle."

Steve Hoffman, co-chairperson of the CIL membership committee and employee of the Berkeley Outreach Recreation Program, was approximately 15 months old before cerebral palsy was officially diagnosed. Before the disease had been pinpointed, one neurological specialist who had examined him for five minutes recommended to his parents that he be put away.

When Steve was old enough to go to school, his parents joined other parents in the Cerebral Palsy Clinic to approach the New York City Board of Education to arrange classes for their children. The city provided a classroom and a teacher and the parents provided transportation and a supportive atmosphere. Steve's mother taught on a rotating basis with other parents of the children. Steve attended this "health conservation" class

until he was later integrated into homeroom and the school's lecture programs. "Talk about psychological shock. I was all alone during elementary school mingling with regular kids in non-talking activities.

"I was able to get a passing grade by doing nothing because I knew I could do a 'crip trip.' During the last two years at school I figured out that my average was 69. When I graduated I came in with a 77 average. I drove my mother crazy because instead of complaining to the school that I wasn't doing anything, she would sit down for hours and hours and write all my homework. She was much happier that way.

"Once I think my average was 80 and that really made my homeroom teacher mad because I hadn't been doing much work. I was a kid like all kids and what did I know. I was going to school in that factory they called a high school in New York City. They locked you up in one city block. They had 3,000 kids, black and white, during a very, very troubled time and they wondered why the students

were angry. I really have a lot of dislike for secondary education and the abominable environment. I mean there is so much cognition-type learning, information that is so dehumanizing to everybody involved.

"So I got out of high school and went to New York University after being told that it would be a pipe dream and that I couldn't live in the dormitory. I trained to be a teacher. I knew I couldn't work in a factory and that I would have to acquire some professional skills.

"In some ways my disability has been an advantage to me. I grew up in a working class Catholic family where all the men sit around the football game and all the women do the dishes. I would have been sentenced to a life as a rugged individualist. If you don't get your way, you just bust somebody's face up. My disability has given me many insights into how people operate and how I operate. Luckily, I became a Berkeley coward riding a three-wheel bike."

Steve thinks that it's important to defuse the anger of many disabled people. He says that the attitude outside Berkeley is one of "staring while covering your eyes." He thinks it's important for the disabled person to be able to make others comfortable and that's difficult to do with so much anger.

"When you go shopping it becomes very acute when you watch mothers keep the kids away from you. I would love to play with all kids and their mothers hold them back. They say, 'I don't want you to touch and I don't want you to talk to that person.'

"One of the first things you can do to demystify disability is bring an old wheelchair into the classroom. Get a walking cane. Get a braille writer. Get every kind of orthopedic equipment you can. Let the kids touch them. Let the kids know there is nothing untouchable about these aids. The minute we get them to touch something we've won part of the battle."



*...the offspring of the inferior,
or of the better when they chance
to be deformed, will be put away
in some mysterious, unknown place...*
Plato, The Republic

CONCLUSIONS

The separate experiences presented in this paper point to several common reactions to handicapped adults. Rejection, pity, and overprotection are the daily reactions the handicapped face. By looking closely at some ill-founded beliefs that influence these reactions, we may gain insight and understanding.

That people with special needs must be constrained in their life goals or aspirations is not supported. The career experiences of the several people interviewed repeatedly did identify career barriers. Guy and Steve were discouraged from attending college. Ed's master teacher and a school principal discouraged him from teaching. For some years, Corbett believed she could teach only the handicapped. These experiences led to career choices that were confused, haphazard or narrowly focused within the parameters of disability. Yet, now each has chosen careers and holds life goals and aspirations that are the same as any adult.

Linked to the myth that the disabled are constrained in their life goals and aspirations is the belief that the disabled are mentally retarded. Mental retardation refers to a delayed and sometimes limited development in learning. Steve reports that in high school he took advantage of this myth to do a "crip trip." He did not perform as well as he could have because his teachers and mother overprotected him. Ed complains that his years of tutoring were unstimulating and that he was not prepared for regular classes. Judy's mother and three and a half hours of home instruction per week put her two to four years ahead of other students in special classes. In one special education class, Jeff found himself to be two years ahead of other students. Pat finds among her disabled clients the frequent complaint that academic expectations of them were not high enough.

Contrary to the popular myth that special needs adults prefer others "like themselves," Judy, Guy, Ed, Jeff and Corbett all comment that their need to be "able-bodied" was so extreme that they denied their disability to the detriment of their intellectual and social growth. It took years for them to overcome this denial and to achieve adaptation.

Closely linked to this denial was the tendency to overcompensate which Judy, Guy, and Jeff describe. Had they, their parents, or society been better prepared to accept their differences and to build sooner on their abilities, they might have been spared wasted energies and frustrations. Corbett comments that it was a long time before she realized that being cured was not a goal.

One of the most prevalent but virtually ignored myths about the handicapped is that they are impotent, that they have no sexual needs. That the handicapped

are asexual is not supported by the narratives. Corbett, Jeff and Ed relate that puberty resulted in additional alienation as their friends began to date and to attend dances from which they were excluded. The handicapped have the same need as other adults for closeness, body comfort, and sensitive interaction.

Other myths further separate people with special needs: they are being punished by God, they are untouchable, they are contagious. All who were interviewed testify to social experiences that operate to set them apart. On the street they are frequently stared at, pointed to, avoided and rejected. Pat and Jeff must initiate talk about their disability to put people at ease. Jeff still finds it easier at times to pass as being able to see.

That adults with physical differences expect help from others is another myth. The narratives speak of self-sufficiency and self-reliance. Yet, for many years, those interviewed were so busy blaming themselves, denying their disability, and coping with an inaccessible world, that they couldn't develop this independence. In addition, parents tended to overprotect them which further restricted their personal need for independence.

SOLUTIONS

This information, from firsthand personal experiences, offers the chance to examine the physical, social and psychological barriers our society has built for people who are different. One solution to the problem of inequality is to seek and hire competent adults with special needs for positions of authority. As productive, integrated adults they will also serve as role models for special needs children and adults. In open interaction with special needs individuals, the public can gain insight into the frustrations and isolation of the human beings who daily face these barriers. In addition, contact with disabled adults in the "real world" can contribute to a heritage upon which special needs children can draw. Unlike other isolated groups who face discrimination in American society, they are only beginning to document their heritage, their accumulated wisdom, the stream of consciousness in which they swim.

Pat, Judy, Corbett, and Jeff talk about the need to be open and direct with children and to allow them to ask questions freely. Steve recommends bringing orthopedic equipment like wheelchairs or braces into classrooms to demystify disability. This equipment could be available through libraries for children to borrow and use at home. This would help break the association between orthopedic equipment and illness. In addition, Pat stresses the need to be positive, to focus on abilities rather than disabilities.

Another means for breaking a connection between disability and illness is to use the term "special needs child" or "special needs adult." These terms are more appropriate substitutes for "handicapped," "disabled" "identified special education child," "learning disabled," "emotionally disabled" or "physically impaired." Implied in the term "special needs" is the understanding that a handicapped person has specific needs that must be served if that person is to receive all the rights and benefits of society. Also implied is the knowledge that at one time or another, all children and adults have special needs.

This statement paper was developed in a project to increase the educational opportunities and life chances for special needs children. Other project materials on this topic include:

- ° "Some Myths and Misunderstandings About People Who Differ - A Listing"
- ° "Me, My School and My Neighborhood - Activities on Differences for Classroom Teachers"

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